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Link to original published version: <http://dx.doi.org/10.1111/j.2044-8287.2012.02069.x>

Citation: Ford S, Howard R and Oyeboode J (2012) Psychosocial aspects of coeliac disease: a cross-sectional survey of a UK population. *British Journal of Health Psychology*, 17(4): 743-57.

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**Psychosocial Aspects of Coeliac Disease: A cross-sectional
survey of a UK population.**

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Abstract

Coeliac Disease (CD) is an incurable autoimmune condition managed by a therapeutic gluten-free diet for life. European studies suggest that the chronicity of CD, the limitations imposed by the need to follow a permanent restrictive diet and the risk of other associated serious diseases can have a negative impact on health-related quality of life (HRQoL) and psychological well-being. However, studies concerning the psychosocial effects of CD in the UK population are scarce. This cross-sectional survey (N=288) explores the illness perceptions and self-efficacy beliefs of adults with CD in the UK and reports their subjective levels of HRQoL and psychological well-being. Results showed that HRQoL and psychological well-being were reduced with levels being comparable to those found in previous related studies. Participants with weak beliefs in the serious consequences of CD and reduced emotional reactions to the condition had a greater likelihood of having enhanced HRQoL, improved psychological well-being and increased self-efficacy. Strong beliefs in personal control over the condition and a greater perceived understanding of CD were also associated with increased self-efficacy. The results suggest that perceived self-efficacy and illness perceptions could play an important role in informing psychological interventions for individuals with CD.

Key words: Coeliac Disease; Gluten-free diet; Psychological Well-being; Illness perceptions; Self-efficacy; Health Related Quality of Life.

Introduction

Coeliac Disease (CD) is a chronic autoimmune disorder in which hypersensitivity to gluten causes damage and inflammation to the small intestine in genetically susceptible individuals (Fera et al., 2003). Those with an untreated condition experience intestinal malabsorption due to partial or total atrophy of the tiny finger like projections (villi) on the surface of the small intestine (Jones, 2007). The condition is also associated with osteoporosis, and fertility problems in women, type I diabetes (Feighery, 2007) and an increased risk of gastrointestinal cancer and non-Hodgkin's lymphoma (West, Logan, Smith et al., 2004). It is estimated that CD may affect up to 1 in 100 people in Western European populations, although many individuals remain undiagnosed (Hopper et al., 2007). Diagnosis is usually achieved through a screening blood test followed by a biopsy of the small intestine to detect villous atrophy. CD can occur at any age, but in adults the peak incidence is in the fifth decade and females are more commonly affected than males (Jones, 2007). The condition is incurable but is managed by a therapeutic gluten-free diet for life. A gluten-free diet (GFD) involves the complete avoidance of all foods made from or containing wheat, rye, barley and usually, oats. This diet is very successful in managing the symptoms of CD as the removal of gluten allows the villi to re-generate therefore leading to the normal absorption of nutrients and restoration of nutritional balance (Häuser et al., 2007).

Although the literature on the immunology and physiopathology of CD is now extensive (Kagnoff, 2005; Barone et al., 2007) the impact of the condition from the individual's view is less well known. The chronicity of the condition, the limitations imposed by the need to follow a permanent restrictive diet and the risk of other associated

diseases can have a negative impact on health-related quality of life (HRQoL) (Casellas et al., 2008) and psychological well-being (Addolorato et al., 2008).

It is therefore not surprising that, increasingly the focus of research is turning to the psychosocial impact of CD on those with the condition and their families (Fera et al., 2003; Hallert, Sandlund & Broqvist, 2003). Much of this research is concerned with psychological well-being and health related quality of life (HRQoL). For example, European studies suggest that depression and lower quality of life affect individuals with CD, and anxiety and depression have been identified as major causes of lower levels of adherence to treatment recommendations (Addolorato et al., 1996) and poor adaptation to the disease (Ciacci, Iavarone, Mazzacca & De Rosa 1998). There is also evidence from Swedish studies that women with CD score lower than the general population on subjective measures of general health and vitality (Hallert et al., 1998) and experience poorer quality of life than their male counterparts (Hallert et al., 2003).

However, studies on the impact of a gluten-free diet (GFD) on HRQoL have produced conflicting results. For example, US-American (Green et al., 2001), Canadian (Zarkadas et al., 2006) and Swedish studies (Roos, Karner & Hallert, 2006) report an average HRQoL for adult celiac sufferers comparable with the general population; whereas studies conducted in Italy (Fera et al., 2003) Northern Ireland (O'Leary et al., 2002) and Germany (Häuser et al., 2006) demonstrate a reduced HRQL compared with the general population or healthy controls.

More research is needed to determine whether affective disorders and reduced quality of life are a feature of CD. At present there is a dearth of studies about the psychosocial effects of CD in the UK population. Knowledge of the prevalence of

psychological distress in the UK coeliac population is important for clinical management, particularly as there is evidence from Italy that psychological counselling can improve adherence to a gluten-free diet in coeliac patients with affective disorder (Addolorato et al., 2004). A better understanding and greater knowledge of the psychosocial effects of CD on sufferers could enhance the clinical management of the condition and ultimately improve the quality of life for adults with the disease.

The two important concepts of illness representation (Leventhal, Nerenz & Steele, 1984; Petrie & Weinman, 1997), i.e. how people interpret current and potential health events or threats, and self-efficacy (Bandura, 1977; 1997), i.e. the belief that an individual has in his or her capability for managing a particular challenge, feature prominently in research concerning responses to and coping with chronic illness. However, at present there has been no investigation of these concepts in relation to CD. Knowledge of these is important for informing therapeutic interventions, to help in the clinical management of the disease.

Although illness perceptions and self-efficacy have been independently constructed they have a common theme at their core. Each posits that individuals' personal constructs of their condition and of their ability to cope with that condition are at the basis of effective self-management (Lau-Walker, 2004). In view of the fact that there is considerable overlap within the two theoretical concepts it seems likely that there will be a relationship between the components of the two models and more specifically that illness representations will be predictive of self-efficacy.

Aims

The survey had three main aims:-

1. To investigate gender differences in quality of life and sense of well-being in adults with CD in the UK
2. To explore the illness perceptions and self-efficacy beliefs of adults with CD in the UK and their relationship with adherence to the gluten free diet.
3. To explore the influence of individuals' demographic characteristics and illness perceptions on self-efficacy, well-being, quality of life and adherence to the gluten free diet.

Method

Design and Procedure

The study design was a cross-sectional postal questionnaire. Adult members (aged 18 years and over) of Coeliac UK (the national UK charity supporting people with CD) were invited to participate in a questionnaire survey designed to investigate the psychological and social effects of living with CD. The survey was advertised in the quarterly Coeliac UK magazine and questionnaire packs were sent to those interested in participating. Some questionnaire packs were also distributed at local Coeliac UK support meetings. Members of Coeliac UK were approached because all members of the Society have been diagnosed with CD via a screening blood test and biopsy of the small intestine. This was an attempt to ensure that those experiencing symptoms of CD, but who had no formal diagnosis were excluded from the study.

The survey pack included an information sheet, consent form, sociodemographic questionnaire and four validated measures described below. Ethical approval was obtained from the University of Birmingham, School of Psychology Research Ethics Committee.

Participants

The majority of participants were women (80%) and of White British origin (95%). Men were significantly older than women (mean difference 8.61; $Z = -4.08$; $P = <0.001$). Adherence to a gluten free diet (GFD) was high with only 13% of participants reporting that they did not adhere all the time. In general, the number of years since diagnosis corresponded with the duration of membership in Coeliac UK. Over half the sample (57%) had received their diagnosis in their forties and fifties. The majority of participants were well educated, married or co-habiting and had professional occupational status. Full sample characteristics are presented in Table 1.

[Table 1 here]

Measures

Perceived Medical Condition Self-Management Scale

A Coeliac Disease-specific adaptation of the Perceived Medical Condition Self-Management Scale (PMCSMS) was used to assess the degree to which the participants felt competent or self-efficacious in managing their CD. The PMCSMS is an 8-item measure based upon the Perceived Health Competence Scale (Smith, Wallston, & Smith,

1995). It was developed as a template that could be made disease-specific and used with any medical condition requiring self-management. It has been successfully adapted for use with patients with diabetes and was found to be a reliable and valid measure (Wallston et al., 2007). Coeliac disease specific questions include “*I handle myself well in respect to my Coeliac Disease*” and “*no matter how hard I try, managing my Coeliac Disease doesn’t turn out the way I would like.*” Responses are rated on a 5-point Likert scale from ‘strongly disagree’ to ‘strongly agree’. Higher scores indicate stronger perceptions of self-efficacy.

The Revised Illness Perception Questionnaire (IPQ-R)

The original Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996) was developed to provide a quantitative assessment of the five components (identity, consequences, timeline, control/cure and cause) of illness representation in Leventhal’s Self-Regulatory Model (Leventhal et al., 1984; 1997). The revised version (IPQ-R) includes a new subscale relating to emotional representations and divides control beliefs into personal attempts to control illness and control of illness by treatment. It has demonstrated sound reliability, discriminant and predictive validity (Moss-Morris et al., 2002).

General Well-being Index (GWBI)

The Psychological General Well-Being Index originally developed in the US by Harold Dupuy (1984) was adapted for use in Britain by Hunt & McKenna (1992) and renamed the General Well-Being Index (GWBI). It provides a self-report of intrapersonal

affective states that reflect subjective well-being or distress. The index consists of questions that cover six affective states: anxiety, depressed mood, feelings of positive well-being, self-control, general health and vitality. The adapted measure has been shown to have good psychometric properties while being short, easy to use and acceptable to participants (Hunt & McKenna, 1992). Responses are rated on a 5-point Likert scale from 'strongly disagree' to 'strongly agree'. The approach adopted in this study was to score the items so that higher scores indicated better psychological well-being.

The Coeliac Disease Questionnaire (CDQ)

The Coeliac Disease Questionnaire (CDQ) is a reliable and valid disease specific instrument for measuring health-related quality of life in adult patients with CD (Hauser et al., 2007). Recently developed in Germany the index has been translated into English. The CDQ comprises four subscales: gastrointestinal symptoms, emotional well-being, social restrictions and disease-related worries. Responses are rated on a 7-point scale from 'strongly disagree' to 'strongly agree'. High scores indicate a good HRQoL.

Adherence

Adherence to the gluten-free diet was measured by one question on a 5-point Likert scale asking participants to rate in general how strictly they maintained their diet.

Data Analysis

The data were analysed using the Statistical Package for the Social Sciences (SPSS 15 for Windows). Reliability analyses were carried out on the four questionnaires using Cronbach's alpha (presented in Table 2). These indicated a high level of internal consistency for all the measures except four subscales belonging to the IPQ-R, namely: Timeline (acute/chronic); Treatment Control; Risk and Immunity. These subscales were removed from subsequent analyses.

With the exception of the adherence scores, the data were found to be reasonably normally distributed and this was confirmed by the Kolmogorov-Smirnov test. Therefore parametric analysis was chosen, except when addressing adherence, where non-parametric analysis was used. To allow comparisons with the results of other studies both medians and means are presented. Preliminary descriptive and univariate procedures were employed before bivariate tests of association (Pearson's) or difference (t-tests) were carried out. Backward stepwise multiple regression analysis was used to investigate the predictive strength of a range of variables on well being, quality of life and self efficacy. Logistic regression was used to look at the influence of a range of variables on adherence.

Table 2 [here]

The dependent variable adherence was split at the median due to its distribution. Up to 25% of missing items on the PMCSMS, IPQ-R, GWBI and CDQ were replaced by

the median of the items of the respective sub-scale. If more than 25% of the items of a subscale were missing the respective measure was excluded from further analysis.

Results

Two hundred and eighty eight out of 433 (66%) questionnaires were received back from participating members of Coeliac UK. Four datasets had to be excluded as they were not accompanied by consent forms. A number of questionnaires were excluded as there were more than 25% missing items as follows:- GWBI 10, CDQ 8, IPQ-R 6 and PMCSM 4. In total, 14 participants were excluded from the main analyses.

Self-Efficacy

The mean scores for the total sample (31.7 s.d. 5.9, range 14-40) indicated a relatively high level of perceived self-efficacy. There was a significant difference in scores between the adherence groups. As predicted, those in the lower group had weaker perceptions of their own self-efficacy to manage their CD ($Z = -2.0$; $P = 0.04$). Conversely, those in the higher adherence group had stronger beliefs in their ability to manage their condition. There was no difference in the level of perceived self-efficacy to manage their Coeliac Disease between men (mean= 32.2) and women (mean= 31.6).

Psychological Well-being

The distribution of GWBI scores for the whole sample ranged from 29 to 110 with a mean of 79.0 (s.d. 15.4) out of a possible top score of 110. Men tended to score slightly higher than women indicating better psychological well-being. These differences were

significant for the total score and the following subscales: Anxiety, Depressed Mood and Self-Control. There was no significance in GWBI scores between adherence groups ($Z=-0.30$; $P=0.76$).

Health Related Quality of Life (HRQoL)

The distribution of Coeliac Disease Questionnaire scores for the whole sample ranged from 61 to 194 with a mean of 152.2 (s.d. 26.4) out of a possible top score of 196 reflecting reduced HRQoL. Reduced HRQoL was defined by scores \leq 10% percentile of the total CDQ score. Men tended to score slightly higher on the CDQ than women, but the differences were only significant for the total scores and two sub-scales: Emotion and Social. There was no significant difference in CDQ total score and adherence group ($Z=-1.25$; $P=0.20$).

Illness Perceptions

Mean scores for consequences (3.5, s.d. 0.82), personal control (4.3, s.d. 0.67) and illness coherence (4.2, s.d. 0.82) were high, reflecting a coherent understanding of CD, strong perceptions of personal ability to control it and strong beliefs about the serious consequences of CD. Participants did not attribute many symptoms to their CD, reflecting a low disease identity (mean 3.3, s.d.2.94). The most important cause identified by participants was genetic risk with over half (52.2%) attributing the development of their condition to their genes. Table 3 shows the mean and median scores for each of the included IPQ-R subscales for men and women and differences between them. The results indicate that women had a significantly higher emotional response to their condition than

men. Women also had significantly stronger beliefs that their CD was caused by psychological factors such as stress and mental attitude; however, there were no gender differences on the other dimensions.

[Table 3 – here]

Associations Between Illness Perceptions and Distress

Table 4 shows Pearson's r correlations between illness perceptions, age and self efficacy, measures of well-being and HRQoL for the whole sample. The majority of the coefficients are modest, lying between 0.40 - 0.65. Those lying between 0.19 – 0.39 are considered low (Cohen & Holliday, 1982). The lower the disease identity of participants the higher their self-efficacy, HRQoL and general well-being scores were. The weaker the beliefs of participants in the severity of their CD, the higher their self-efficacy, HRQoL and psychological well-being scores were. Stronger perceptions of personal control over the condition and a clearer understanding of CD were also associated with increased self-efficacy and improved HRQoL. The weaker participants' beliefs that CD was variable over time and the lower their emotional responses were to CD the higher their self-efficacy, HRQoL and psychological well-being scores were. Total scores for the CDQ and GWBI were also strongly correlated (Pearson 0.77, $P=0.01$).

[Table 4 – here]

Predicting General Well-being, HRQoL and Self-Efficacy

The results of backward stepwise multiple regression analyses to investigate predictors of general well-being, HRQoL and self-efficacy were conducted. A number of variables were entered for each of these analyses, i.e. gender, age at diagnosis, years since diagnosis, all the subscales of the IPQ and adherence but those which did not significantly contribute to the variance in the outcome variables were systematically eliminated from the models. In all cases, models were produced which found that a number of variables, in combination, explained a significant degree of variation in the outcomes.

In relation to well-being (GWBI total): Adjusted R square = .401; $F_{4,261} = 45.43$, $p < 0.0001$ (using the backwards stepwise method). Contributing variables were: Age at diagnosis, Identity, Timeline cyclical and Emotional representations. In relation to Health Related Quality of Life (CDQ total): Adjusted R square = .629; $F_{6,262} = 76.63$, $p < 0.0001$ (using the backwards stepwise method). Contributing variables were: Age at diagnosis, Identity, Consequences, Illness Coherence, Timeline cyclical and Emotional representations. Finally, in relation to self-efficacy (PMCSMStotal): Adjusted R square = .554; $F_{6,264} = 56.96$, $p < 0.0001$ (using the backwards stepwise method). Contributing variables were: Age at diagnosis, Personal Control, Consequences, Illness Coherence, Timeline cyclical and Emotional representations.

Predictors of GFD adherence

Table 5 shows the results of a binary logistic regression analysis to predict high adherence to a gluten-free diet (GFD). Variables entered in to this regression were age, all illness perception subscales, self-efficacy, well-being and health-related quality of life. The most predictive independent variables were older age, strong beliefs in the serious consequences and weak beliefs in the cyclical nature of CD (or conversely beliefs in the chronicity of the condition). This means that the older participants were and the stronger their beliefs in the seriousness of CD the more likely they were to stick to a GFD. Furthermore, the weaker participants' beliefs in the cyclical nature of CD the more likely they were to adhere to a GFD. The correct classification rate for the model was 86%. None of the outcome measures, self-efficacy, general well-being and HRQoL were strong predictors of high adherence.

The internal validity of this model was good. In the omnibus test the coefficients were significant ($P = <0.0001$) and the significance level in the Hosmer-Lemeshov (Goodness of fit) test was 0.86, above the predefined P-value of 0.05, thus confirming goodness of fit.

[Table 5 – here]

Discussion

This study investigated the psychosocial impact of CD on a UK adult population in terms of health-related quality of life and psychological well-being. It is also the first to investigate the illness perceptions of individuals with CD.

HRQoL, Psychological Well-being and Self-Efficacy

The results for HRQoL are in line with previous research which indicates that lower quality of life affects individuals with CD. The mean and total distribution of scores for the CDQ were comparable with those found in the German Coeliac Society population by the authors of the instrument (Häuser et al., 2007). In this German study to validate the CDQ the mean score for participants (n=516) who belonged to the German Coeliac Society was 151.1 (s.d. 25.2). Reduced HRQoL was defined by scores \leq 10% percentile of the total CDQ score which was 11% of the sample. There were significant differences between men and women for all sub-scales, reflecting better health related quality of life for men. In the current UK population, the univariate analyses showed that men had higher scores than women on the total scale and two subscales, Emotion and Social. This indicates that women were more emotionally affected by their CD than men and found the condition more socially restrictive. However, it could not be demonstrated by multivariate analysis that there was an association between male gender and increased HRQoL.

For psychological well-being the results were similar in that GWBI scores indicated a reduced overall level of psychological well-being. The mean GWBI of this CD population was slightly lower compared to individuals with long-term health problems drawn from a UK primary care population and considerably lower when compared to a healthy sub-set drawn from the same sample (Hopton, Hunt, Shiels & Smith, 1995). In this UK sample the distribution of GWBI scores ranged from 29 to 109 with a mean of 82.2 (s.d. 14.6). Forty five percent of patients had a limiting long-term illness, health problem or handicap In a healthy sub-group of this sample i.e. those with no long-

standing illness and absence of anxiety and depression, GWBI scores ranged from 54 to 109 with a mean of 94.0 (s.d. 10.9). In the CD sample, there were also slight differences between the mean scores of men and women on this measure for total score, and the subscales of anxiety, depressed mood and self-control, with men having a better outcome. Once again however, gender difference was not demonstrated in the multivariate analysis.

The mean PMCSMS scores showed a relatively high level of perceived self-efficacy in this CD population meaning that individuals generally felt confident with managing their condition. Those in the lower adherence group had significantly reduced self-efficacy compared with those in the high adherence group. This is in line with early diabetes research that found patients adhering to dietary advice were more likely to report feeling competent to self-manage their diabetes (Talbot et al., 1997). However, the PMCSMS was not found to predict adherence in the multivariate analysis. Furthermore, no significant difference was found between the scores of men and women unlike the findings in a recent study of people with Diabetes where men scored higher than women (Wallston et al., 2007).

Illness Perceptions

In general the participants reported a coherent understanding of their condition with strong perceptions of their personal ability to control it and strong beliefs about the serious consequences of CD. Few differences in illness perceptions were identified between men and women. The finding that women were more likely to respond more emotionally to their CD than men may be a reflection of different ways of coping

between men and women (Hallert et al., 2002). Women also believed more strongly than men that psychological causes such as stress had some bearing on the development of their condition. Again, this is perhaps a reflection of differences in western society at large in which women tend to report more psychological symptoms than men (Wittchen, 2002).

There were associations between weak identity perceptions and increased HRQoL and enhanced general well-being. Weak beliefs in the serious consequences of CD increased the likelihood of increased self-efficacy and HRQoL. Strong perceived personal control increased the probability of a higher self-efficacy score. Strong perceived illness coherence tended to increase the likelihood of better self-efficacy and HRQoL. A reduced emotional response to CD and weak beliefs that the condition was cyclical in nature increased the probability of better self-efficacy, good HRQoL and enhanced psychological well-being. At present there exist no similar studies investigating the illness perceptions of individuals with CD so that comparisons cannot be made. However, in a study focusing on illness representations and outcomes in irritable bowel syndrome (Rutter & Rutter, 2002) the authors found similarly that the reporting of serious perceived consequences was associated with reduced quality of life and poorer scores for anxiety and depression. The high correlation between CDQ and GWBI scores suggest a close relationship between psychological well-being and HRQoL.

Adherence

The adherence rate was high with 87% of participants reporting that they stuck to a GFD all of the time, the remaining 13% reported that they adhered most or some of the time.

The small numbers of participants showing low adherence to the diet make the analysis of adherence less robust.

Predictors of Psychological Well-being, HRQoL, Self-efficacy and Adherence

In the regression analyses, the only consistent predictor of all four outcome measures was Timeline cyclical. In all cases, weaker beliefs in the cyclical nature of CD were related to better outcome. Age at diagnosis, perceived consequences and emotional responses also played an influential role in a number of outcomes. Being older at diagnosis, holding weaker beliefs in the serious consequences of CD and reduced emotional responses were more likely to be associated with better health-related quality of life and self-efficacy; whilst being older at diagnosis and having a less intense emotional response was also associated with better well-being. Older age had a significant influence on adherence and enhanced psychological well-being. A weaker CD identity was more likely to be associated with an improved HRQoL. Greater perceived illness coherence also increased the likelihood of a better HRQoL and higher self-efficacy. Stronger beliefs in personal control were associated with increased self-efficacy.

Although strong beliefs in serious consequences was a likely predictor of adherence, results reported in the paragraph above indicated that weaker beliefs in serious consequences increased the likelihood of enhanced psychological well-being, HRQoL and Self-efficacy. However, there was no evidence in this study to suggest that those in the high adherence group had poorer scores than the low adherence group on any of these outcome measures. This interaction effect needs further investigation in future research.

Limitations of the Study

Some limitations of the study should be born in mind. The participants were recruited from adult members of Coeliac UK leading to a possible selection bias. Although the sample represented a small proportion of adult members of Coeliac UK they were representative of the profile of the Charity's membership, i.e. predominantly white Caucasian and of high educational level. Due to this profile the results may not generalise to people with CD of lower educational level or ethnic groups whose beliefs about CD and illness perceptions may differ. Further, there is evidence that membership of a self-help organization is predictive of reduced life satisfaction (Janke, Klump, Gregor & Häuser, 2005). However, there are no comparative data available between individuals with CD with and without membership of Coeliac UK. It is possible that there is a further response bias from individuals with reduced psychological well-being and HRQoL being more likely to return the questionnaires. Therefore, it seems unlikely that the findings of the study are representative of the UK general population of people with coeliac disease. Conversely this group of individuals is the only available large UK sample studied to date.

The cross-sectional nature of this study should also be considered, since this means that the results show only associations between variables and prohibit conclusions being drawn about causality. The inclusion of a control group or healthy non-CD group would have facilitated the interpretation of scores for HRQoL and psychological well-being by providing normative data. Measuring adherence to a gluten-free diet can be challenging, particularly when using a self report measure. Measurement of adherence may have been enhanced with the addition of recent coeliac antibody blood test results.

However, this is not always an accurate measure of adherence. Further research should consider a series of adherence measures in order to gain an accurate measure of dietary self-management. Finally, it should also be mentioned that the data are self-reported which may bias the answers to sensitive questions such as dietary compliance. However, anonymity of the data was maintained to help minimize this potential bias.

Conclusions

Amongst adult members of Coeliac UK there was evidence of reduced HRQoL and decreased psychological well-being. The gender differences in quality of life found in previous research were not repeated in the multivariate analyses used in this study. More research is needed in the UK Coeliac Disease population using robust methodologies such as case control or longitudinal studies to investigate this potential difference further.

Further investigation is also required into possible differences in quality of life and well-being between those who adhere to a GFD and those who do not. Self-efficacy and illness perceptions appeared to be influential factors in this study and could play a role in informing psycho-education for individuals who might benefit from therapeutic intervention to improve GFD adherence and enhance psychological well-being. More information is needed on the link between self-efficacy, illness perceptions and adherence to a GFD. Further knowledge of these factors is important for informing therapeutic interventions, to help in the clinical management of Coeliac Disease.

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Table 1 Sociodemographic Characteristics of Study Sample (n=284)

Variable	Number (%)	Mean (SD)	Range	Median	25th – 75 th Percentile
Sex (female)	227 (80.0)				
Age All		54.0 (14.6)	19-85	56	44-65
Male		61.0 (13.6)	23-85	63	53-70
Female		52.3 (14.4)	19-84	54	43-63
Duration of membership in Coeliac UK					
<1-5 yrs	133 (46.8)				
6-20 yrs	103 (36.3)				
>20 yrs	48 (16.9)				
Years since diagnosis					
<1-5 yrs	127 (44.7)				
6-20 yrs	103 (36.3)				
21-40+ yrs	53 (18.6)				
Age at diagnosis					
<1-20 yrs	34 (12.1)				
21-40 yrs	85 (30.1)				
41-50+ yrs	163 (57.8)				
Adherence to a GFD					
All of the time	246 (86.6)				
Most/some of the time	37 (13.4)				
Marital status					
Married	184 (64.8)				
Co-habiting	26 (9.2)				
Separated/divorced/widowed	36 (12.8)				
Single (never married)	-				
Highest educational level	36 (12.8)				
No qualifications	63 (22.3)				
Secondary School	67 (23.6)				
Vocational training	116 (40.8)				
University degree					
Occupational status (previous or current)	137 (48.9)				
Professional	71 (25.4)				
Managerial/technical	21 (7.4)				
Non-manual skilled	24 (9.0)				
Manual skilled/partly skilled	27 (9.7)				
Non-skilled/home-maker					

Table 2 Reliability coefficients for subscales of all measures

Measure and Sub-scale	Number of items	Cronbach's alpha
PMCSMS		
Total Scale	8	0.92
IPQ-R		
Identity	14	0.80
Timeline (acute/chronic)	6	0.51*
Consequences	6	0.79
Personal control	6	0.81
Treatment control	5	0.51*
Illness coherence	5	0.90
Timeline (cyclical)	4	0.92
Emotional representations	6	0.88
Psychological causes	6	0.87
Risk	6	0.67*
Immunity	3	0.42*
GWBI		
Positive well-being	4	0.86
General health	3	0.86
Depressed mood	3	0.91
Anxiety	5	0.85
Self-control	3	0.88
Vitality	4	0.87
CDQ		
Gastrointestinal symptoms	7	0.82
Emotional well-being	7	0.91
Social restrictions	7	0.85
Disease related worries	7	0.81

Table 3 Mean and Median Scores for Illness Perceptions

IPQ-R Subscale	Means (standard deviations) and Medians (ranges)				Difference test
	Females (n=219)		Males (n=55)		
Identity	3.5 (3.02)	3.0 (1-12)	2.9 (2.58)	3.0 (1-12)	t=-1.12 p= .26
Consequences	3.5 (0.82)	3.6 (1.3-4.8)	3.5 (0.80)	3.6 (1.6-5.0)	t= 0.29 p= .77
Personal control	4.3 (0.62)	4.5 (2.1-5.0)	4.2 (0.84)	4.3 (1.0-5.0)	t= -1.28 p = .20
Illness coherence	4.2 (0.79)	4.4 (1.8-5.0)	4.2 (0.95)	5.6 (1.0-5.0)	t= -.37 p=. 72
Timeline cyclical	2.3 (1.10)	2.0 (1.0-5.0)	2.0 (0.99)	2.0 (1.0-4.5)	t= -1.44 p= .15
Emotional responses	2.6 (0.96)	2.5 (1.0-5.0)	2.2 (0.98)	2.0 (1.0-5.0)	t=-2.68 p= .008*

Note: *= significant difference

Table 4 Correlations (Pearson) between age and Illness Perceptions, and Outcome Measures

Total Scores n= 274			
	PMCSMS	CDQ	GWBI
Age	0.21 ^{**}	0.28 ^{**}	0.25 [*]
Identity	-0.33 ^{**}	-0.58 ^{**}	-0.44 ^{**}
Consequences	-0.43 ^{**}	-0.53 ^{**}	-0.37 ^{**}
Personal Control	0.37 ^{**}	0.21 ^{**}	0.08
Illness Coherence	0.55 ^{**}	0.41 ^{**}	0.29 ^{**}
Timeline cyclical	-0.50 ^{**}	-0.57 ^{**}	-0.49 ^{**}
Emotional representations	-0.62 ^{**}	-0.66 ^{**}	-0.53 [*]

Note: ^{*} $p = 0.01$, ^{**} $p \leq 0.001$

Table 5 Logistic regression analysis of factors predicting high adherence to a GFD

Independent Variables	Odds Ratio	95% CI	B	P-value
Age	1.04	1.01-1.07	0.04	0.002
PMCSMS	1.07	0.97-1.17	0.07	0.14
GBWI	0.97	0.93-1.02	-0.03	0.17
CDQ	0.99	0.96-1.02	-0.01	0.54
Identity	0.96	0.81-1.13	-0.03	0.65
Consequences	1.15	1.03-1.28	0.14	0.009
Personal control	1.08	0.96-1.20	0.07	0.16
Illness coherence	1.01	0.90-1.13	0.01	0.83
Timeline cyclical	0.87	0.77-0.98	-0.14	0.02
Emotional representations	0.94	0.85-1.05	-0.05	0.31